



## **Children and Youth with Special Health Care Needs (CYSHCN) Needs Summary**

**2024**

# Introduction

Every 5 years, the Washington State Department of Health (DOH) assesses the health of children, parents and caregivers, and families to support the Maternal and Child Health Block Grant (MCHBG).

DOH collects information through a Discovery Survey, key informant interviews, and facilitated discussions. This information helps identify the priorities to guide our work. It also helps us better understand the needs and challenges impacting the health of women, pregnant people, young people, children and youth with disabilities and their families.

The **Children and Youth with Special Health Care Needs (CYSHCN) domain** promotes connected systems of care for children and youth with diverse, special care needs from birth through their transition to adulthood. These children and youth may have or be at increased risk for chronic physical, developmental, behavioral, or emotional conditions. Their complex needs mean multiple areas of their life may be affected.

## Key Themes from Community and Partners

### Community-based Discovery Survey themes:

- **Health care access:**
  - Gaps in **access to physical, mental and behavioral health service, respite care**, and personal care hours for CYSHCN parents.
  - Need for services for children with complex medical conditions without developmental concerns, and therapies for CYSHCN with other disabilities that affect their daily life.
  - Not enough **primary care, mental health, and dental care** providers are well-versed in understanding and accommodating CYSHCN.
- **Caregiver availability:** Challenges finding affordable, accessible, quality, and CYSHCN-friendly caregivers.
  - Child care is essentially non-existent for CYSHCN ages 11-17, as these children are too old for day care and too young for adult care.
- **Financial assistance:** CYSHCN families noted a high need for **financial assistance** and **payments for their caregiving responsibilities**.
- **Community and belonging:** Respondents expressed a desire for opportunities to build **community belonging** for CYSHCN and their families. They also reported a need for more sensory-friendly, ADA accessible, CYSHCN-friendly events and **recreational spaces**.
- **Special education:** Survey responses highlighted the need for special education services to be funded in school systems.
- **Local resources:** Rural area CYSHCN families reported the need for more access to local resources and services tailored for CYSHCN.

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Medically underserved area with provider shortages. Lack of green spaces to recreate. Lack of inclusive spaces for my child losing his ability to walk and see. Lack of safe, licensed childcare to ensure equitable economic opportunities for families.

(Discovery Survey participant)

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## Key informant interviews, facilitated discussions, and local health partner reports:

- **Provider reimbursement:** Low reimbursement rates for service providers and its impact on provider availability for CYSHCN was a noted concern.
- **Long wait times:** Families experience significant delays for developmental screening, assessment, and diagnoses. These delays reduce a family's ability to get their CYSHCN connected to resources and therapies.
- **Transportation barriers:** Families often have to travel hours to reach specialists, adding to their stress and costs.

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Transportation is a barrier for families who need to travel out of county for specialized health care visits. There is a lack of healthcare specialists in our area and families frequently need to travel 1-3 hours for these visits. A feeding team is greatly needed for kids with feeding issues, especially those who are being followed by a maxillofacial team.

(LHJ Needs Assessment respondent)

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## Research Findings

In addition to listening to community members, local health champions, and program partners, we also conducted a literature review to identify top priorities and recommendations for children and youth with special health care needs in Washington.

Key finding include:

- Early universal screenings and connections to services are critical but often delayed.
- Most communities have significant gaps in services like child care for infants and toddlers with high needs, substance use treatment for any age group.
- Access to a diet and nutrition support for any age group is extremely difficult to find.
- A [2023 survey](#) of individuals with intellectual disabilities and their caregivers highlighted the need for disability equity, including better ADA accommodations. Reducing ableism and more inclusion in program decision-making and workforce representation also came up.



## How the health of CYSHCN in Washington Compares to the Nation

In 2021, about 21% of children in Washington had special health care needs, compared to 19% nationally. CYSHCN and their families in Washington are less likely to receive needed care coordination, have a medical home, and receive family centered care than those in the rest of the country.

- Over the half the families or 56% said they didn't get the care coordination they needed, ranking Washington last in the country.
- Nearly two-thirds or 63.8% said they did not have a functioning medical home, compared with 59.3% nationally.
- 19.3% of parents or other family members with CYSHCN in Washington left a job, took a leave of absence, or cut down on hours worked because of child's health or health conditions compared to 18.1% nationwide.

**Table 1. Washington Comparison for National Performance Measures<sup>1</sup>**

Indicator	Washington		State Rank	United States	
	%	95% CI		%	95% CI
Did not receive needed care coordination	56.0	(48.2-63.4)	49	44.4	(42.9-45.9)
Did not have a medical home	63.8	(57.3-69.7)	46	59.3	(58.0-60.6)
Did not receive services to prepare for the transition to adult healthcare	73.9	(64.7-81.4)	14	77.9	(76.3-79.4)
Did not have family centered care	20.4	(14.8-27.4)	42	17.8	(16.7-19.0)

<sup>1</sup> National Survey of Children's Health (NSCH), 2022

**Table 2. Health Care Access and Quality Indicators<sup>2</sup>**

Indicator	Washington		United States	
	%	95% CI	%	95% CI
Did not have a chance to speak with a healthcare provider privately, without parent or caregiver	33.4	(24.9-43.2)	40.9	(38.9-42.9)
Did not receive both preventive medical and dental care in the past 12 months	22.7	(17.5-29.0)	27.0	(26.6-29.2)
Very difficult to get mental health treatment or counseling	32.0	(23.4-42.1)	19.0	(17.5-20.6)
Very difficult to get specialist care	13.4	(7.9-22.0)	9.1	(7.8-10.7)

<sup>2</sup> National Survey of Children's Health (NSCH), 2022

Gaps and Opportunities

- Education and support:
  - Slightly more CYSHCN ages 1-17 in Washington, 31.9% received services under a special education or early intervention plan during the 2021-2022 school year, compared to 30.8% nationwide (Table 3).
  - 13.2% of CYSHCN students ages 5-21 served by the Individuals with Disabilities Education Act (IDEA) were identified with autism in Washington compared to 12.8% nationwide.

Table 3. Age Started Special Education or Early Intervention Plan<sup>3</sup>

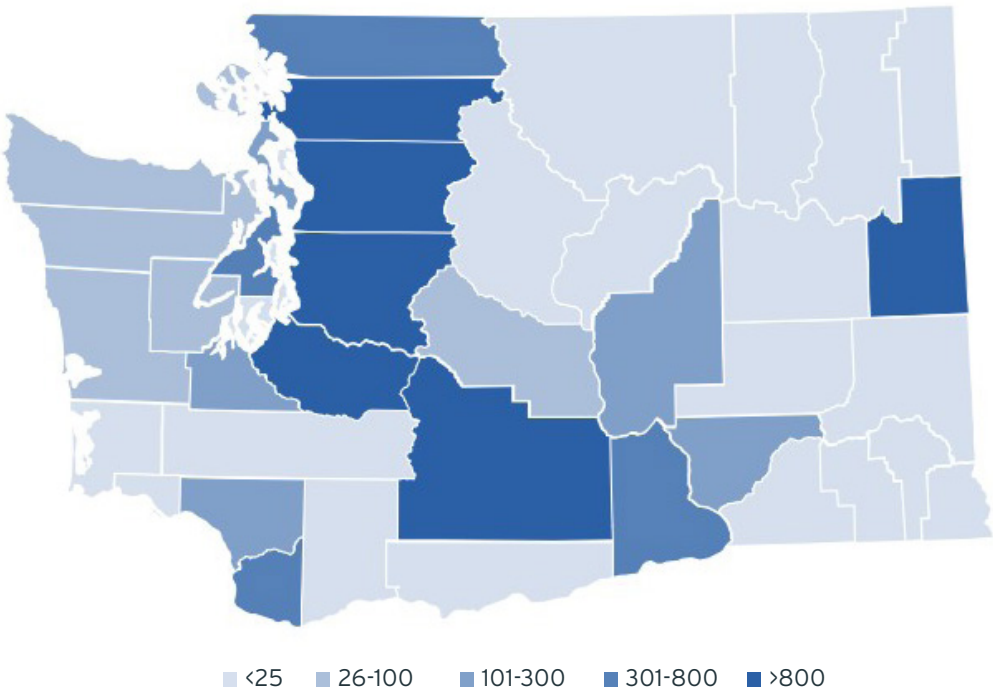
Age group	Washington		United States	
	%	95% CI	%	95% CI
Less than 3 years old	15.0	(9.0-24.0)	18.3	(16.9-19.9)
3-5 years*	45.6	(35.0-56.5)	40.3	(38.3-42.4)
6-17 years*	39.4	(29.4-50.4)	41.3	(39.3-43.4)

3 National Survey of Children's Health (NSCH), 2022

The map and figures below explore patterns in services to CYSHCN in Washington and indicators of student success, mental health and well-being.

Figure 1. Number of CYSHCN Served by LHJs and Neurodevelopmental Centers

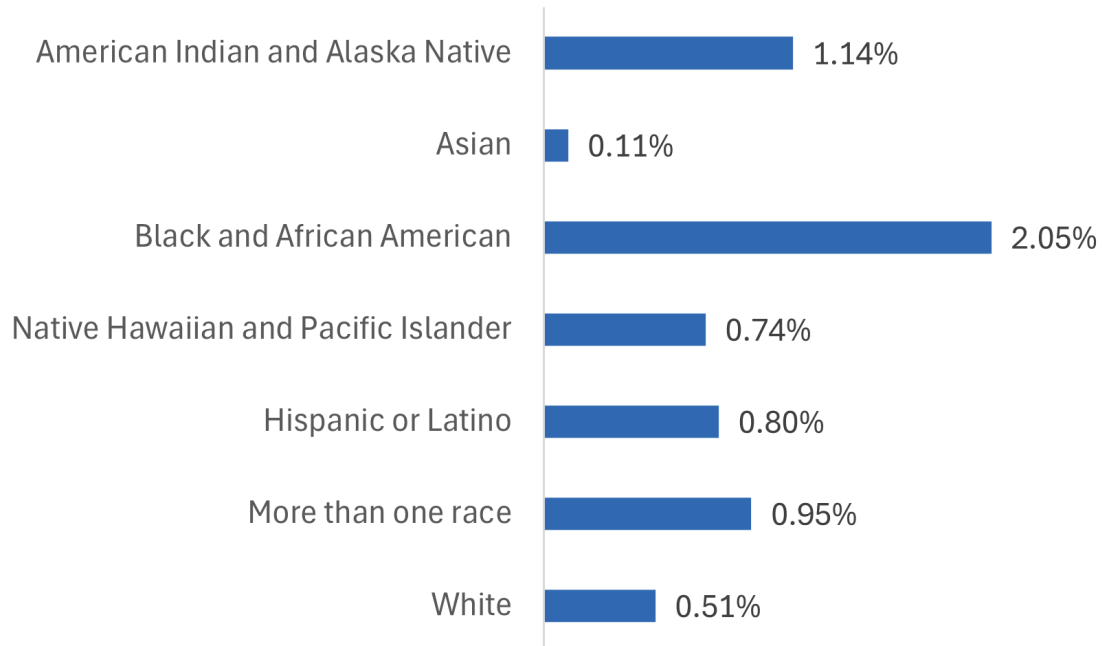
According to Child Health Intake Form data, 14,268 children and youth with special health care needs were served by county health departments and Neurodevelopment Centers of Excellence in 2021.



**Statewide efforts to increase access:** The Washington State Parks and Recreation Commission is updating its Transition Plan to address barriers to accessibility for people with disabilities. An interactive map on the [ADA Accessible Recreation | Washington State Parks](#) website allows for ADA features to be selected so that people with disabilities can access state parks' natural, cultural, and recreational features. Finding ADA-friendly recreational spaces is hard to find, including data on use and specific ADA-accessible elements.

### Figure 2. Suspension or Expulsion Greater Than 10 Days Among CYSHCN by Race or Ethnicity <sup>4</sup>

The figure 2 below shows the rate of school suspension and expulsion greater than 10 days by race and ethnicity for students with disabilities.



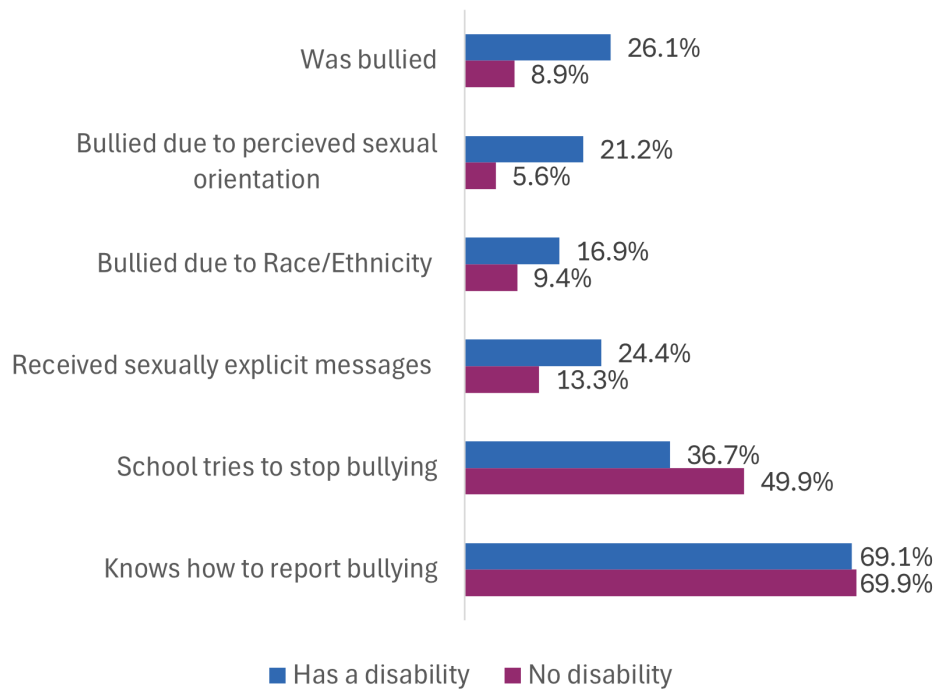
<sup>4</sup> Washington State Annual Performance Report LEA District Profiles, OSPI, 2022

- During the 2022-23 school year there were 163,280 students with disabilities enrolled in school in Washington.
- 6.9% of students with disabilities received a short-term or long-term suspension, or expulsion for a discipline related incident, compared to 2.9% of the 947,364 students without disabilities.
- Black students with disabilities had the highest rate of suspensions or expulsions exceeding 10 days in a school year.
- 2.05% of Black students with disabilities were out of school for more than 10 days related to a discipline incident compared to 0.51% of White students with disabilities.

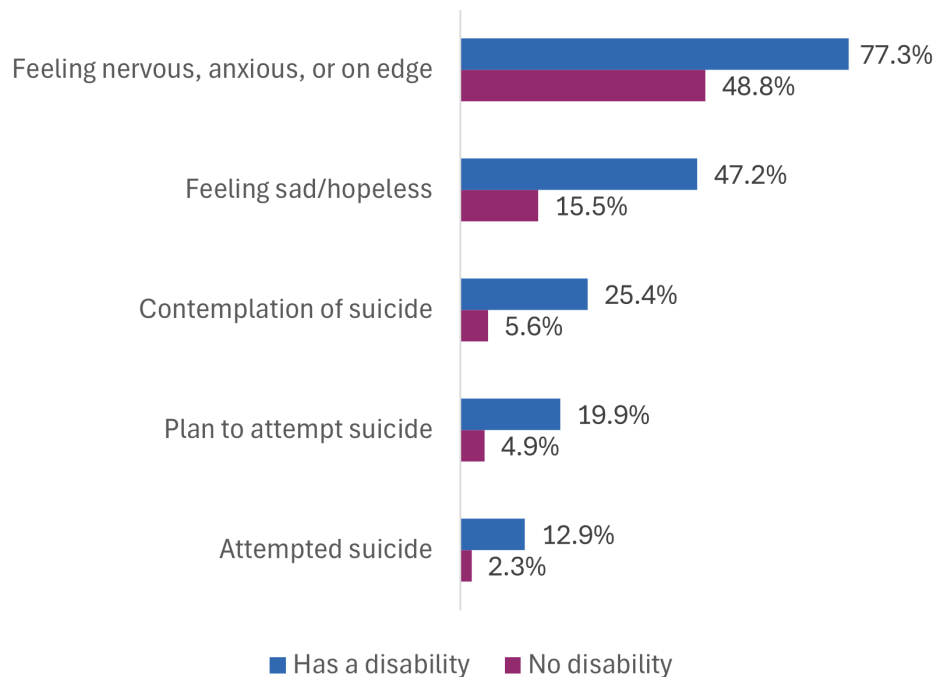
### Bullying, Harassment, and Mental Health

Figures 3 and 4 shows bullying and harassment and mental health status for 10th grade students with disabilities. Students with disabilities are at greater risk for experiencing bullying, harassment, anxious feelings, depressive feelings, and suicidality than students without disabilities.

**Figure 3. Bullying or Harassment**



**Figure 4. Mental Health and Suicidality<sup>4</sup>**



<sup>4</sup> Healthy Youth Survey (HYS), 2023